



PERSPECTIVES ON PATIENT CONSENT: IS CONSENT DEAD AND SHOULD WE EVEN CARE?

CONSENT QUALITY AND INTEROPERABILITY
UNDER THE NEW ADMINISTRATION

MASSACHUSETTS HEALTH DATA CONSORTIUM

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- **PRIVACY IN FEDERAL LAW:**

- The Constitution contains privacy rights in a number of places:
 - 1st, 4th and 5th Amendments
 - Implied in the 14th Amendment:
Griswold v. Connecticut, 381 U.S. 489 (1965)
- Federal Trade Commission Act (15 U.S.C. § 45)

- **CONSENT IS THE OPERATIONAL ANALOGUE OF THE RIGHT TO PRIVACY**

- Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972); cert. denied 409 U.S. 1064 (1972): “The root premise is the concept, fundamental in American jurisprudence, that ‘every human being of adult years and sound mind has a right to determine what shall be done with his own body. . . .’”
- **Consent with regard to records is address in HIPAA**

- **STATE LAW (Massachusetts as an example):**
 - Alberts v. Devine, 395 Mass. 59 (1985)
 - Mass. Gen. L. ch. 111, § 70E, the “Patients’ Right’s Statute”
 - Mass. Gen. L. ch. 93H, “Data Security” -- Standards for the Protection of Personal Information of Residents of the Commonwealth (201 C.M.R. 17.00)
 - Dozens of statutes deal with the disclosure of sensitive information
- **In others states, these rights also are found in statutes and in the case law**

“We have established the most enormous medical entity ever conceived, and people are sicker than ever.”

- “Presumed consent” appears to be on the rise:
 - HIPAA was a significant milestone in presumed consent for use in:
 - Treatment
 - Payment
 - Health care operations
 - “Opt” in “versus” opt out: organ harvesting proposal in UK
- The pressure to reduce costs is ever increasing:
 - “To lower health care cost, cut medical errors, and improve care, we’ll computerize the nation’s health record in five years, saving billions of dollars in health care costs.” Pres. Obama’s weekly radio address, January 24, 2009
 - Is presumed consent needed to make this work?
- Consent is viewed as just a concept, something that carries costs, but no tangible benefits

“O brave new world”

- Are laws about to change, either to make sharing of information easier, or more difficult?
- Is the concept of consent ultimately incompatible with a RHIO/HIE?
- Are we willing to give on certain elements of consent in order to reap the benefits?
- Is presumed consent really consent?
- Have we fully considered the negative ramifications of presumed consent?

“There was, of course, no way of knowing whether you were being watched at any given moment”

- New demands for privacy are coming, even as more information is being shared:
 - GINA
 - New federal legislation
 - FTC Red Flag rules
 - State identify theft laws
- Is this a trend?
- What are the implications of this trend for the role of consent in health information exchange?
- Are we headed for a collision?



“How I Learned to Stop Worrying and Love the Bomb”/
“Always Look on the Bright Side of Life”

- The fact that we are discussing these issues is a positive sign
- Mistakes will be made
- Compromises will be reached
- Pure consent may diminish, but not disappear



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